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Community Care: PEOPLE WITH MENTAL HANDICAP



35 PINWOOD GREEN AVE.,
BALLBRIGGAN,
CO. DUBLIN.
PHONE 413308

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Policy Document

NATIONAL ASSOCIATION FOR THE MENTALLY
HANDICAPPED OF IRELAND

£2.00

The National Association for the Mentally Handicapped of Ireland. (NAMHI) is a voluntary organisation of those who work on behalf of people with a mental handicap: is non-sectarian and non-political: is a multi-disciplinary body involving, among others, parents, doctors, nurses, teachers, psychologists, therapists, administrators, training personnel, family members and friends of people with a mental handicap.

AIMS

The aims of the National Association are:-

1. To promote the general welfare of mentally handicapped persons.
2. To disseminate knowledge of mental handicap.
3. To encourage the highest possible standards of treatment, education, training and employment of mentally handicapped people.
4. To encourage the formation of local and regional associations for mentally handicapped people and to facilitate communication and co-operation between persons engaged in work in the field of mental handicap or associated fields.
5. To give advice and guidance to parents and relatives of mentally handicapped persons.
6. To arrange or assist in arranging and providing for the holding of lectures, conferences, meetings and discussions on subjects of general or special interest in the field of mental handicap.
7. To promote and engage in research.

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Telephone (01) 766035

TABLE OF CONTENTS

TASK FORCE COMMITTEE	1
ACKNOWLEDGEMENTS	2
INTRODUCTION.....	4
SECTION 1 RECOMMENDATIONS.....	6
SECTION 2 A CONTEXT FOR COMMUNITY CARE	8
1. Historical Perspective.....	8
2. Definition of Community Care	11
3. Who can live in the community ?	11
4. General Principles.....	12
SECTION 3 PRE-REQUISITES FOR COMMUNITY CARE.....	13
1. Planning	13
2. Finance	16
3. Prevention	19
4. Standards of Care	21
5. Staffing	23
6. Community Helpers (Volunteers).....	25
SECTION 4 COMMUNITY CARE - A MODEL	26
1. Day Services	27
2. Home Options	28
3. Supports for people with mental handicap.....	30
4. Services for people with additional handicaps	35
5. After-Care	39
6. Supports to Families	42
7. Practical Supports	50
SECTION 5 THE FUTURE - ESSENTIAL ELEMENTS.....	52
1. Community Awareness	52
2. Future of Residential Centres	54
3. Research	55
REFERENCES.....	57
SUBMISSIONS.....	60

35 PINWOOD GREEN AVE.,
BALLBRIGGAN,
CO. DUBLIN.
PHONE 413308

COMMUNITY CARE
TASK FORCE COMMITTEE

Mary Prenderville	-	Daughters of Charity Services, St. Vincent's Centre, Dublin. (Chairperson).
Audrey Arthure	-	St. John of God Brothers, Drumcar.
Dr. Noirin Buckley	-	Past Chairperson, N.A.M.H.I.
Jerry Buttimer	-	Cope Foundation, Cork.
Gerry Flannery	-	St. Raphael's Parents and Friends Associa- tion.
Mary Rawlins	-	Helping Hands, Tallaght.
Bridann Reidy	-	St. Michael's House, Ballymun.
Noel Sinnott	-	Downs Syndrome Associa- tion.
Bob Sillery	-	Brothers of Charity, Galway.

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The Document was initiated by the St. Raphael's Parents and Friends Association when they put forward a Motion at the 1988 A.G.M. A special word of thanks is due to this Association for highlighting the need for such a Document.

Brother Thomas O'Grady, President, N.A.M.H.I., set up a Task Force Committee on Community Care to examine all the aspects of this complex issue. His constant encouragement, support and practical help to the Committee assisted greatly in our deliberations.

In the early stages of exploring the subject, the Task Force consulted a wide variety of people, so as to elicit their views - people with mental handicap, families, frontline staff, service providers and professional groups. Their responses were invaluable and much of the report is based on their contributions.

With regard to the parent survey carried out at the 1988 Regional Meetings, I would like to thank Seamus Scanlon, St. John of God Brothers, Drumcar, for doing the analysis of the survey. Unfortunately, we had insufficient time available to interpret the findings of this survey for inclusion in this report.

I owe a great deal of gratitude to all the Task Force Committee Members (See list on previous page) who worked tirelessly and with great enthusiasm throughout the past few months to organise and complete this Document. All the Committee Members contributed to writing up this report.

I do, however, owe a special word of thanks to Bridann Reidy and Dr. Noirin Buckley who undertook a lot of additional work in the final stages of the report writing.

I would also like to extend my thanks to Gerry Ryan, General Secretary, N.A.M.H.I., who has been available for consultation and assistance at all times. Also a special word of appreciation is due to Loretta Gallagher and Olive Crowther in the N.A.M.H.I. Office for their secretarial help and general support.

Finally, my sincere thanks are due to Margo Sherman, St. John of God Brothers for typing this report.

Mary Prenderville,

Chairperson

TASK FORCE - COMMUNITY CARE

I N T R O D U C T I O N

Community Care is a concept that has been growing and evolving over the past few decades. Its meaning has changed over time. In the early years of its development, it predominantly meant care outside Residential Centres. In recent times there is a greater emphasis on improving the quality of life of people with mental handicap and a recognition of the need to provide a wide range of supports to the individuals concerned and their families.

The issue of Community Care is one that has caused families a lot of concerns. Many fear that Community Care means family care with little or no support. These concerns have been escalating as the number of people with mental handicap living in the community increases. In recent years there has been a general halt in the development of the kind of supports essential to ensure a good quality of life for individuals and their families. Parents, especially those who are ageing, who require alternative accommodation for their daughters/sons face lengthy waiting lists with no reassurances of places being available.

This background of growing dissatisfaction and confusion about Community Care, prompted the following Motion to be put forward at the 1988, N.A.M.H.I., A.G.M. :

That this A.G.M. directs the incoming Executive to draw up a draft policy document on Community Care and all its ramifications for submission for approval to next year's A.G.M. This draft document should include among other things :-

- (a) The Executive's definition of Community Care.
- (b) The support of Residential Centres in the context of Community Care.
- (c) The future of Residential Centres in the context of Community Care.

This Policy Document aims to examine the many complex issues raised in this Motion. It also looks at Community Care with due regard to the Irish historical context. Our early services were developed mainly through the efforts of non-statutory organisations and offered mostly residential type provision. The Health Boards throughout the country had limited involvement in service provision.

The current trend towards Community Care demands a much greater involvement of the various Health Boards, especially in view of the fact that they have responsibility for providing Community Care programmes. It is essential for the future that a strong partnership approach is adopted so that Health Boards, non-statutory service providers, clients and their families can work cooperatively in developing the appropriate services to ensure a successful Community Care Programme.

RECOMMENDATIONS

1.1. Who can live in the community ?

We recommend that any person whose quality of life can be enhanced by living in the community should have access to this option.

1.2. Principles

We recommend the formulation of basic principles as a prerequisite to planning and organising service delivery.

1.3. Planning

We recommend the development of clear National, Regional and local Planning Structures that will ensure an effective model of community care for people with mental handicap and their families.

1.4. Consultation

We recommend that the planning structures be organised in such a way as to involve clients and their families in a meaningful way.

1.5. Prevention

We recommend the development of a comprehensive preventative programme at all levels - especially the provision of genetic counselling to all family members who require it.

1.6. Standards

We recommend the introduction of appropriate standards of care at all levels of service delivery.

1.7. Services for People with Mental Handicap

We recommend the provision of all necessary DAY ACTIVITIES, HOME OPTIONS and SUPPORTS to suit individual needs.

1.8. Adults

We recommend that the plight of adults with mental handicap be designated a national crisis and urge the immediate development of appropriate services.

1.9. Family Supports

We recommend that families be fully supported in their role of caring for their children/adults with mental handicap, through the provision of support services.

1.10 Community Awareness

We recommend that N.A.M.H.I. in consultation with appropriate Agencies, initiate and co-ordinate a national programme of community awareness.

1.11 Resources

We recommend that the Government make available the necessary funding to ensure an effective model of community care.

1.12 Residential Centres - Future

We recommend that the suggestions put forward for the future of residential centres in this report be given consideration.

1.13 Information Systems/Research

We recommend the development of information systems and the use of research as aids to planning and evaluating effectiveness of service delivery.

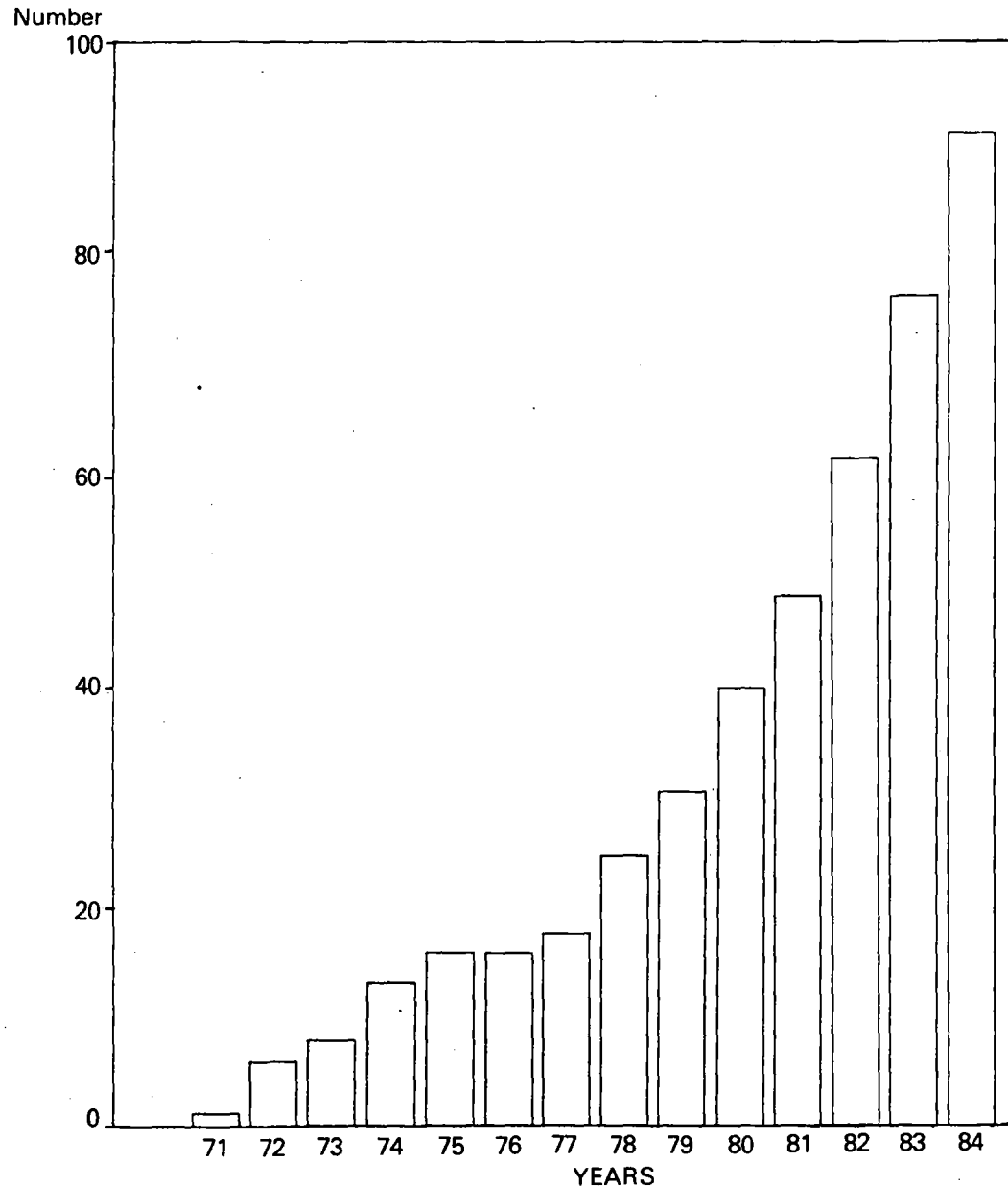
SECTION 2 A CONTEXT FOR COMMUNITY CARE

2.1. HISTORICAL PERSPECTIVE

- 2.1.1. In Ireland, as in many other countries, the development of our services began with the provision of specialist/segregated services. Our many residential centres still existing around the country provided the principal form of care to children/adults with mental handicap. The first centre to open in Dublin was Stewarts Hospital in Palmerstown in 1870. This was followed in 1926 by the Daughters of Charity when they opened St. Vincent's Centre, Navan Road.
- 2.1.2 The majority of the services have evolved through the pioneering work of religious orders and voluntary bodies. These were later complemented by the many locally based Parents and Friends Groups who initiated their own service. The Government recognised the value of these organisations and have been satisfied to provide the necessary funding.
- 2.1.3 Until around the 1960's the key role played by the State in providing services to people with mental handicap, was mostly centred in the psychiatric hospitals. In recent years many Health Boards throughout the country are taking a more active role, not only in service provision, but also in adopting the role of coordinating the already existing organisations.
- 2.1.4 In general, it is true to say that the services have evolved in a fragmented and patchy fashion without any coherent planning. In those early years no clear set of principles and rights for people with mental handicap were enunciated. This has resulted in glaring inequities in the level of resources and services available to citizens with similar needs.

- 2.1.5. This evolution of predominantly non-statutory agencies has become a relatively unique feature in Western Europe. It allows for greater potential innovativeness, as well as less bureaucracy. In recent years, such agencies have taken the lead in shifting the emphasis from institutional care towards the development of community based residences.
- 2.1.6. This shift in emphasis towards community care signifies the adoption during the past two decades of the twin philosophies of "Normalization" and "Integration". In essence, this form of care provides the citizens with mental handicap with as normal a lifestyle as possible.
- 2.1.7 There has been a marked increase in the number of community based residences for people with mental handicap. The following diagram illustrates a steady increase in the number of residences opening each year (See Diagram 1).
- 2.1.8 For community care to be a viable option, it must provide a comprehensive range of services that are well resourced and supported. There has been a misconception that a community based model of service will be a cheaper option than the more traditional institutional provisions. To provide adequate community based services is not a cheap option, however, it can provide a quality of life in keeping with the aspirations of the World Health Organisation - "Targets for Health for all by the year 2000". (1)

DIAGRAM 1:
Number of CBRs in Ireland for each year 1971-1984



Taken from Article: Community Based Residences: Supporting the staff, Maura Boyle and Denise Kavanagh.

2.2. DEFINITION OF COMMUNITY CARE

- 2.2.1 Community Care is the option, which, if properly implemented will enable the person with mental handicap to live safely within the community rather than within the isolation of an institution. It is the vehicle which should enable the person with mental handicap to participate in a wide variety of ordinary activities in the community.
- 2.2.2 When it is not possible for a person with mental handicap to live with her/his family, it is important to make available a range of alternative home options - e.g. adoption, foster care, supervised homes in the community, supported living arrangements etc.
- 2.2.3 The other essential ingredients in providing an effective model of community care are the provision of appropriate day facilities and also support services to people with mental handicap and their families.
- 2.2.4 Finally, community care implies the active involvement of the wider community in caring for its citizens with mental handicap and also supporting their families to the fullest possible extent.

2.3. WHO CAN LIVE IN THE COMMUNITY ?

- 2.3.1 This is a very crucial issue and one that has been discussed very widely, especially in recent years with the increased emphasis on community care.

2.3.2 At the present time a significant number of people with all ranges of mental handicap, and all ages, are living in the community. Many live with their families, while others live in the community based residences as well as other home options.

2.3.3 It is felt that any person whose quality of life can be enhanced by living in the community should have access to this option.

2.3.4 It is important to remember that placing a person with mental handicap in a community setting, does not of itself improve the persons quality of life. What makes the difference is the level of integration for the person as well as the provision of appropriate day and support services.

2.4. GENERAL PRINCIPLES

2.4.1 In planning services for people with mental handicap, it is essential to formulate fundamental principles on which to base the development of services. These must include an emphasis on human rights and individual needs.

They include :

- having the same basic rights as other citizens in society.
- the right to respect, acceptance and dignity.
- the right to live with his/her family, or alternatively, in an environment that best enhances his/her development.
- the right to a full life programme with additional supports to enable the person to develop fully.
- the right to make personal choices and decisions.

SECTION 3 PRE-REQUISITES FOR COMMUNITY CARE

3.1. PLANNING

3.1.1 In order to meet the needs of people with mental handicap and their families in a comprehensive manner, it is vital that we develop a clear national, regional and local planning structure. This form of structure is particularly important in the building of a community care model of service provision. This structure must commence with a realistic assessment of needs.

3.1.2 Ireland is one of the few European countries with a fairly up-to-date census of its citizens with mental handicap (2). This readily available information confirms the fact that the current level of services is not sufficient to cater for the identified numbers of people who need services now or who will be needing services in the very near future.

3.1.3 It is important to recognise that the presence of mental handicap in a family is not only a difficult experience in the early stages, but it is often a life long commitment which in many instances increases as the person with mental handicap and their parents grow older. This inevitably results in a need to plan appropriate services to meet the life long needs.

3.1.4 It should be remembered that the Nation has committed itself to the preservation of life, no matter how fragile or damaged. There is a moral obligation, therefore, on the State to provide the necessary resources to ensure the quality of life of every citizen with a disability.

3.1.5 In Ireland, the services are still at a developmental stage. We still have people with mental handicap with a) no services; b) people in inappropriate settings (in psychiatric hospitals); and c) in inadequate services.

3.1.6 It is essential that we engage in concrete planning so as to develop a comprehensive network of services and supports that are available throughout the life time of each person. Our planning process must take account not only of current needs but must take cognizance of the numbers coming on stream for all the different services.

3.1.7 Demographic trends in the field of mental handicap, have, through the census (3) shown that there is now an increasing number of middle aged people with mental handicap requiring services.

3.1.8 Due to improved health care, longevity is likely to be prolonged even further. Hence we can expect an increasing number of elderly people coming on stream. This presents a major challenge to Service Providers, Health Boards, the Government and the community in general.

3.1.9 There is no statutory provision for consultation and involvement of consumers and families in the planning process. This situation is deplorable and runs directly contrary to the targets of W.H.O., for example.

Target No 29 calls for "cooperation and team work between Health personnel, individuals, families and community groups (4).

3.1.10 An important feature in shifting towards community care is the necessity to plan and allocate adequate funding. Successful examples of transition to community services in the U.K. all embodied a period of time when "transitional budgeting" was provided so that two types of service ran in parallel for a period.

3.1.11 The aspirations of the W.H.O. Target No. 3 that "By the year 2000, disabled persons should have the physical, social and economical opportunities that allow, at least for a socially and economically fulfilling and mentally creative life", are not reflected in current resource provisions. The current inadequately funded and insufficiently planned services for people with mental handicap does not offer the possibility of equality of opportunity with other citizens.

3.1.12 N.A.M.H.I. are eagerly awaiting the report of the Review Body, set up by the Department of Health. It is hoped that many of the issues raised in this document will be addressed and fully dealt with in this report.

3.2. FINANCIAL IMPLICATIONS

- 3.2.1 In common with other factors relating to the provision of a community-based service to people with a mental handicap, the financing of such services has given rise to much debate. The policy of the present and previous governments in relation to reducing the "National Debt", and the consequent reduction in capital and revenue spending by the State has adversely effected all health services in this country.
- 3.2.2. In Mental Handicap Services these budgetary policies have had, in many areas, a catastrophic effect, and given that these services have traditionally been grossly underfunded, the goal of providing a comprehensive service to all persons with a mental handicap, and their families, is now hardly possible in the foreseeable future given current trends.
- 3.2.3 It is generally accepted that persons with a mental handicap enjoy a more fulfilling and more ordinary lifestyle in living in a community setting rather than in an institutional setting. Little public information regarding the cost effectiveness of community against institutional-type service is available in this country. One published study (6) however, indicates that the cost of community services are not greater than those of institutional services and this statement is verified by similar studies undertaken in other countries (7). Experience to date in Ireland would indicate that some people with higher dependency needs require additional resources to ensure a good quality of life.

- 3.2.4 Future provision of community care services must tackle the specific problems of adults. In particular those adults on long waiting lists for accommodation, many of whom reside with ageing parents. Also those in inappropriate settings, i.e., psychiatric hospitals, will require services. For many parents their heart rending question is - What will happen to my daughter/son when we die ?
- 3.2.5 It is in the area of inappropriate placement that major capital funding is urgently required, not to upgrade existing facilities, but to provide an appropriate range of home options in the community. In the overall context of the State Capital Programme, these costs are not enormous, and with an enlightened approach towards the transfer of revenue funding, additional revenue costs would be negligible.
- 3.2.6 In the context of the overall provision of services to persons with a mental handicap the State has gradually assumed control of practically all of the funding and, with this control, exercises an almost complete monopoly of the allocation of funds and how they may be utilised.

This approach has two primary effects :

- a) The State decides the amount of service that will be provided, and where and when it will be so provided.

- b) The user has no choice but to accept what is provided, and in whatever locality.

3.2.7. In an effort to achieve greater equity, we recommend that the feasibility of direct resource allocation to each individual person with mental handicap be investigated. This would necessitate the establishment of an acceptable "index of need" system whereby the scale of an individual's need could be evaluated and extra weighting given to multiple handicaps and severe degrees of dependency. The actual mechanics of how the resources would be used would also need to be carefully organised to ensure both the possibility of choice and the necessity for continuity and stability, of service provision.

3.2.8 A similar scheme operates in Vancouver B.C. (8). This system has many advantages, the most obvious being :-

- a) the user now has the choice of service.
- b) the power of the State to decide for the user has been greatly diminished. The basic principle of this type of funding is that it offers choice to people with mental handicap and their families.

3.3. PREVENTION

3.3.1 There is always an obligation to engage in research into causation and prevention in the field of mental handicap by those professionals working in this area. Much of the preventative work within the community is undertaken by the Community Care Area Medical Team either alone or in conjunction with other Agencies.

3.3.2 For a preventative programme to be effective it is essential that it contains the following elements. Some of these are already in existence.

3.3.3. Holding, in conjunction with Maternity Hospitals, Ante-Natal Clinics at local level in high density areas. It is important to make Ante-Natal care available to those in most need. The areas that are most in need in Dublin are Tallaght, Finglas and Ballymun. There are similar areas throughout the country.

3.3.4 Providing good child care is essential. This can be achieved by a) a Public Health Nurse visiting all newly born babies to check their general health and to ensure that the P.K.U. test was done, b) holding Child Welfare Clinics where children can be seen by Doctors, free of charge under the age of five years. In this way mental handicap could be detected at an early stage.

3.3.5 Provision and promotion of vaccination schemes in conjunction with General Practitioners, so as to ensure the uptake of vaccination is kept at an acceptable level. This includes vaccination against diphtheria, whooping cough, tetanus, measles, mumps and rubella.

- 3.3.6 Provision of developmental clinics for children aged eight months, one year and two years. This could have a screening function where developmental and other disabilities could be picked up.
- 3.3.7 By operating the register for people with mental handicap effectively at Health Board level, this would allow the Director of Community Care to refer on children suspected of having mental handicap. The referral can be made to the local Mental Handicap Agency offering an assessment, diagnostic and advisory service.
- 3.3.8 Health Education is needed so as to make local communities aware of the hazards of smoking and drinking in relation to low birth weight and mental handicap. It could also focus on the dangers of environmental hazards such as lead as a possible cause of mild mental handicap.
- 3.3.9 The Directors of Community Care should be demanding the availability of adequate genetic counselling for all the family members who require it.
- 3.3.10 In the future it is important that Community Care personnel are in touch with such new conditions as the occurrence of Alzheimers Disease in people with Downs Syndrome which will influence planning of services for elderly.
- 3.3.11 The provision by Community Care Teams of adequate family support for vulnerable families is essential. It is important to lessen the cycle of deprivation and the amount of socially induced handicap

by providing adequate housing, income support, good health care, social work assistance to vulnerable families etc.

- 3.3.12 In promoting the concept of prevention within the community, it is important that a partnership approach is established between all functioning Agencies i.e. Health Boards, Mental Handicap Agencies, and Maternity Hospitals. These Agencies are dependant on one another in carrying out their function of preventing mental handicap.

3.4. STANDARDS OF CARE

In Ireland today we have a very complex range of services for people with mental handicap and their families. The most important elements of these services is how effectively they are in meeting the evolving needs of their clients. This poses the crucial question of how to measure their effectiveness.

- 3.4.2 The move towards Community Care has meant a shift away from large residential centres which are mostly contained within a small geographical area towards the development of home options within the general community which are typically spread over a much wider area. This emphasis, though offering the least restrictive environment, calls for a greater level of management co-ordination and monitoring.

- 3.4.3 This type of structure places enormous demands on staff and increased their level of responsibility. Formerly, while operating within the residential complex, staff had easier access to supervisory and management personnel. Within the Community care system this access is inevitably restricted. There is now, more than ever before, a need for staff to have a clear set of guidelines in relation to standards of care. The absence of such standards can inevitably lead to poor quality of service delivery.
- 3.4.4. It is also essential to build in an evaluation system. Paul Berry defines evaluation as "the systematic process of measuring the relevant efficiency of a residential service in attaining the defined objectives" (9). He emphasises the need for ongoing evaluation in order that successful monitoring and development of services provided takes place.
- 3.4.5 As the number of people with mental handicap living in the community increases, clearly it is essential that an examination of the various evaluative instruments is undertaken with the aim of identifying the most appropriate methods in the Irish context.
- 3.4.6. A number of effective models of evaluation have been developed nationally and internationally. N.A.M.H.I. have developed a very comprehensive Standards of Care document primarily for use in residential centres. In South Wales, Nimrod (New Ideas for the care of Mentally Retarded People in ordinary dwellings 1976 - 1983), developed a number of instruments for the analysis of client improvement and to enable optimum individual programmes to be created.

P.A.S.S. (Programme Analysis of Service System), U.S.A. was developed by Wolfensberger in 1972. It is an evaluative procedure with the aim of measuring human service provision. It is based on a number of value systems, the most notable being the principle of normalization. The New Zealand Institute of Mental Retardation (Incorporated) have also developed a standard for residential services (10).

- 3.4.7 In Ireland we have no specific framework available to ensure the needs of people with mental handicap are met. Each element of the life of a person with mental handicap is dealt with through a number of fragmented statutory and administrative procedures.
- 3.5. STAFFING - COMMUNITY BASED HOMES
- 3.5.1 The provision of suitable staffing in community based homes will determine the success of such homes. It must be recognised that the roles of staff in these situations can be demanding and highly responsible. It is therefore essential to recruit staff with the best possible personal qualities and attitudes, as well as high levels of motivation, competence, skill and expertise to ensure the highest possible standards of care.
- 3.5.2 The roles that staff are expected to undertake in community based homes, will differ greatly from those operated in traditional settings. It can be expected that many staff who have spent their formative working years in residential centres may have some difficulty adjusting to the new roles expected of them in the community homes.

- 3.5.3 Investing the necessary resources in training and development programmes for staff is an essential component in achieving successful community care projects. Such programmes should be ongoing in nature so as to keep abreast of new developments nationally and internationally.
- 3.5.4 An Bord Altranais are in the process of exploring the possibility of devising an appropriate training programme for frontline staff in community based residences. N.A.M.H.I. have met them to discuss this matter.
- 3.5.5. In their paper "Community Based Residences : Supporting the Staff", Maura Boyle and Denise Kavanagh point to the need for support and supervision of direct care staff. "Support and supervision are two aspects of management which have direct pertinence to one another. Supervision is most effective when it is done in a constructive, supportive framework and generally speaking, supervision is best regarded as an essential component of support" (11).
- 3.5.6 In their paper, they also emphasised the need for staff at all levels to have common goals and objectives "the more clearly and explicitly their objectives are defined, the more easily they can be achieved and measured. This leads to a sense of common purpose and fulfillment of achievements, which is ultimately encouraging and supportive of staff efforts (12).
- 3.5.7 The growing trend for people to live in the community calls for greater social skills, higher standards of behaviour and an awareness of social norms for each individual. These skills were not as necessary for people living in residential centres.

Therefore, it is important that people with mental handicap have access to a variety of people who can enable them to develop to the maximum their full potential. The multidisciplinary team working in partnership with people with mental handicap and their families offers great variety in terms of knowledge, skills and expertise.

3.6. COMMUNITY HELPERS/VOLUNTEERS

- 3.6.1 In his book WHO CARES ? "Community Involvement With Handicapped People" (13), Roy Mc Conkey states his preference for using the term 'community helper' rather than volunteer worker. As he rightly points out volunteers attached to services in the past were predominantly involved in fundraising activities. Many still are and this type of involvement is indeed very valuable.
- 3.6.2 The new roles for 'community helpers' that have been evolving alongside the development of community care are expanding greatly. The contributions that such helpers make complement greatly the overall provision of services.
- 3.6.3 It has been clearly established that when community helper schemes such as Break Away are well planned, organised, monitored and evaluated that they contribute greatly to the quality of life of people with mental handicap (14). It is also crucial to offer training and ongoing support to helpers.
- 3.6.4 Although we strongly support the development of community helper projects, we do not endorse their use as a cheap option or as an alternative to providing trained staff.

SECTION 4 COMMUNITY CARE - A MODEL

4.1. DAY SERVICES

- 4.1.1 Both children and adults with mental handicap have wide ranging needs for a variety of day service provisions. Children of different ages will need a variety of educational services available to them whereas adults may require the provision of workshops, supported employment opportunities etc.
- 4.1.2 In planning the delivery of day services for people with mental handicap the following are some factors which should be addressed.
- a) Day Services should be available as a matter of right to any person with mental handicap who may wish to avail of such services.
 - b) The location of day services facilities should be such that in rural areas, no person should need to travel more than 30 kms on a single journey, and in urban areas their travelling time should not exceed 30 mins. Where adequate public transport is unavailable or inappropriate, a suitable transportation system should be provided to clients.
 - c) A comprehensive assessment service should be offered to each client and a suitable training programme based on the assessment should be implemented.
 - d) The qualifications of staff in day services should reflect the needs of the client group.
- 4.1.3 The following range of day service provisions should be available to day people with mental handicap of different ages and levels of ability.

i) PRE-SCHOOLS/PLAYGROUPS

During the pre-school years children with a mental handicap will need access to playgroups and pre-schools in order to have opportunities to mix and play with other children of their age. Around the country there are many services running playgroups exclusively for children with mental handicap. There are also, however, many playgroups which cater for a mixture of children who may or may not have a mental handicap. There appears to be advantages and disadvantages in both settings. The social advantages of mixing with normal children must be balanced against the specific educational and developmental needs which may in some cases be met more appropriately in specialist services.

ii) SCHOOLS

Children with mental handicap may have different schooling needs depending on their age and ability level. For some children their educational needs may be best met in a "Special School" setting where the curriculum is specifically geared towards their special learning difficulties. Other children, however, may have their learning needs met more appropriately in a more integrated learning environment in an ordinary national school.

iii) DEVELOPMENTAL DAY CENTRES

Children with a severe mental handicap have a right to education. Developmental Day Centres which provide education, training and care for children with severe and profound mental handicap should be available locally as close to the family home as possible.

iv) VOCATIONAL TRAINING

Young people with mental handicap who have left school may require a further period of education and training prior to employment. Traditionally this type of training/ongoing education have been available in Vocational Training Centres. Recently however, some people with mental handicap have received training in particular vocational skills through more general training schemes e.g. FAS Schemes.

v) EMPLOYMENT

People with mental handicap have the same rights and need for meaningful work as their peers who do not have a mental handicap. While unemployment for the population at large is high in this country, the opportunities for people with mental handicap to secure positions in open and supported employment are limited at present. Securing employment for people with mental handicap whether in an open or supported setting is currently a major area of need in our services which will require input of resources and support.

4.1.4 There will also be a continuing need for day activity programmes which may be more segregated than other employment facilities, for people with profound or multiple handicaps who may require more specialized care settings.

4.2.1 HOME OPTIONS

The provision of a home base is of crucial importance to all people in society. It is particularly necessary for our vulnerable citizens. Although the overall aim for children and for many adults with mental handicap is to live in the family home, this option is not always possible.

There is therefore a need to develop a range of alternatives such as foster care, adoption, houses in the community, "digs", and supported living arrangements to suit individual needs.

4.2.2 FOSTER CARE.

This option has been underdeveloped in this country, in spite of the fact that many Government Reports have advocated its development (15) (16). Experience to date of children who have been fostered indicates that it is a very viable option. Insufficient staffing and funding at Health Board level has resulted in this option being pursued only minimally. For those children with mental handicap who are in foster care throughout the country, there are variations in the allowances payable to foster parents. This issue needs examination with a view to reasonable standardisation of payments.

4.2.3. ADOPTION

The presence of mental handicap should not restrict a child's access to being adopted. In the past where mental handicap was suspected in relation to a child, this often prevented the child being considered for adoption.

4.2.4 COMMUNITY BASED RESIDENCES

Within the community care context, this form of accommodation is the most popular option. It provides the individual person with mental handicap with an opportunity to live in an environment that is close to the norm as possible. Depending on the individuals concerned, it provides levels of supervision. This is a very reassuring aspect for parents.

In planning community based homes throughout the country it is important that they are located adjacent to the general population, close to families, friends, convenient to services i.e. schools, public transport, shops, churches and entertainment/recreational facilities

4.2.5 SUPPORTED LIVING ARRANGEMENTS

a) DIGS

For many people with mental handicap living in digs would provide an ideal combination of relative independence with many of the practical supports required. It is an option which has not been utilized well in the Irish context as yet and one that has good potential.

b) FLATS

Flat dwelling for some people with mental handicap represents a real option. It provides an opportunity for an advanced level of independence. For some people the support of a warden might be sufficient to give individual independence.

4.2.6 SUMMARY

The need for the development of home options and in particular, houses in the community must be a priority for the future. There are a total of thirty two local housing authorities in the twenty six counties, each of which have their own priority waiting lists. It is essential that people with mental handicap be given very high priority on these lists. In particular, where new developments are being built it is imperative to designate a quota of houses for people with mental handicap.

4.2.7 ADULTS

It is important to recognise that there is a major crisis in relation to all services for adults, especially accommodation provision. This has been a growing problem over many years and requires immediate attention.

4.3. COMMUNITY SUPPORTS

4.3.1 People with a mental handicap and their families are entitled to whatever additional support from their local community and professional services they need in order to live a life as fully integrated as possible within their local community. Additional support services for people with mental handicap should include the following :

4.3.2 PROFESSIONAL SUPPORT SERVICES

People with mental handicap will need additional help and guidance in order to develop their potential for learning and independence in many different areas. In general persons with mental handicap should have available to them a range of support services which would include Direct Care Workers e.g. Nurse; Speech Therapist; Physiotherapist; Occupational Therapist; Social Worker; Psychologist; Teacher; Home Teacher; Community Nurse; Specialist Medical Services etc.

At different stages during his/her life a person with a mental handicap will require different types and degrees of support. A range of support services should be available to meet varying needs as they arise.

4.3.3. SUPPORTED RECREATION AND LEISURE

People with a mental handicap have the same needs for a worthwhile and enjoyable life-style as other people have. They may however need particular help in pursuing and taking part in a variety of social and leisure activities. Leisure opportunities for people with a mental handicap may take many forms.

4.3.4 Traditionally the most common provision has been the "Special Clubs" where activities are provided specifically for people with a mental handicap. Over the years facilities such as Arch Clubs, Gateway Clubs, Special Olympics etc. have been very successful in providing supported leisure activities all around Ireland, to people with mental handicap of varying age groups. Many innovative schemes have also recently been started, whereby both children and adults with a mental handicap have had opportunities to mix with their non handicapped peers taking part in local recreational events and using community leisure facilities. The use of volunteers in encouraging integrated leisure activities has been found to be a valuable source of support.

4.3.5. People with mental handicap should have available to them a range of both "integrated" and "special" leisure facilities. Wherever possible, however, people with mental handicap should be encouraged to use local community leisure facilities.

4.3.6 DEVELOPING RELATIONSHIPS

People with a mental handicap frequently also have additional difficulties in the area of developing social skills.

They often have only very limited opportunities to meet and socialize with people their own age. Many people with mental handicap live isolated lives with very few friends. Many volunteer schemes such as the Friendship Schemes, CASA etc. have provided invaluable support to people with mental handicap by helping them to meet new people and develop new relationships. Such schemes should be widely available for people with mental handicap.

4.3.7 COUNSELLING

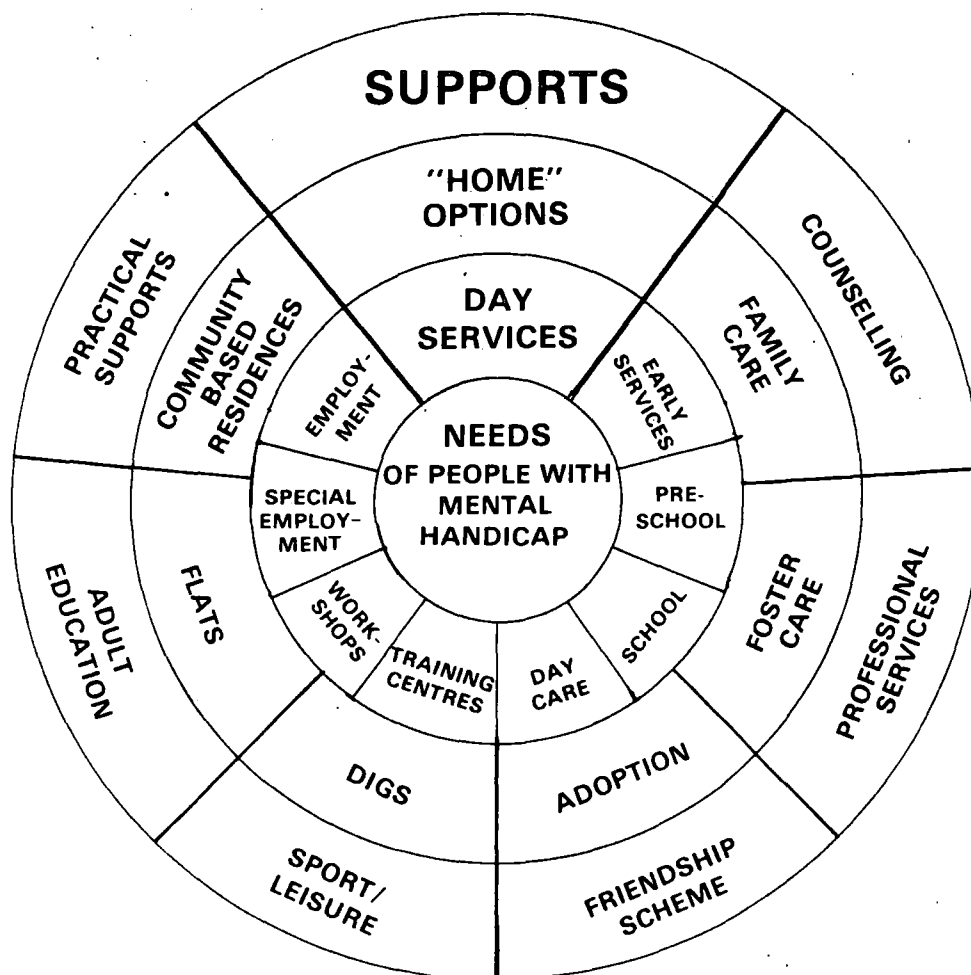
- People with mental handicap who are living at home with their families or who are living in community based residences will need the support of a counselling service to help them to cope with the various crises, changes, upsets etc. which may happen at different stages during their lives.
- Research has shown that people with mental handicap often may experience personal difficulties in adjusting to increasing levels of independence in their lives. If counselling is readily available to these people, further additional problems can be prevented if they are dealt with at an early stage.
- A range of counselling techniques should be available in order to support people with mental handicap with varying needs and levels of ability.

The following S.W.I.M., Social Workers in Mental Handicap, Diagram 2, illustrates the range of supports needed for people with mental handicap.

DIAGRAM 2:

S.W.I.M.

NETWORK
OF
SERVICES
for people with
Mental Handicap



4.3.8 ADULT EDUCATION AND TRAINING

People with a mental handicap generally need to continue developing their personal independence skills over a much longer period than their non handicapped peers. Many people in fact will need to have training and support throughout their lifetime. Whether the person with mental handicap is living in the family home or in a community based residence they should have available to them ongoing training facilities in the following areas:

- Self Help Skills
- Domestic Household Skills
- Social Academic Skills
- Community Skills
- Interpersonal Skills
- Leisure Skills
- Self Advocacy Skills

4.3.9 It is envisaged that while much of the ongoing training necessary will be provided by existing services, wherever possible appropriate people with mental handicap should be encouraged to take part in local Adult Education Classes which may also be able to meet some of their training needs.

4.4. SERVICES FOR PEOPLE WITH ADDITIONAL HANDICAP

4.4.1 Wherever possible people who have other disabilities in addition to mental handicap should be incorporated into the regular mental handicap services. It will be important, however to ensure that these peoples needs can be met by the regular mental handicap services without undue disadvantages to other clients within the service.

4.4.2 PHYSICAL HANDICAP

People who have physical handicaps will have additional needs arising from problems with transport, use of equipment, access to buildings etc. Every effort should be made to meet these needs so that people with a physical handicap can make as full use as possible of existing services.

4.4.3 People with physical handicaps may have specialized education and training needs. They should receive this training in a setting with people who have similar levels of ability and interests as themselves.

4.4.4 Specialized equipment and resources should be made available for people with physical handicaps so that they will be able to live as independent a life as possible. Funding should be available for equipment for example, computers, special switches etc. which would allow these people some regulation of their environment.

4.4.5 PEOPLE WITH VISUAL IMPAIRMENT AND HEARING DIFFICULTIES

Special funding should be available for people with visual impairment and hearing difficulties so that equipment and resources will be readily available to them.

4.4.6 Training programmes should be available to people with hearing and visual impairment in order to minimize additional disabilities resulting from their handicaps e.g. they may need special help to learn alternative forms of communication.

4.4.7 PEOPLE WITH DISTURBED BEHAVIOUR

People with a mental handicap and disturbed behaviour have special needs within our services. It is important that we evaluate a persons disturbed behaviour within the context of the environment where it occurs.

4.4.8 Services need to have available to them a variety of resources and service options in order to deal successfully with disturbed behaviour. The first option for the person with mental handicap should always be to have their behaviour dealt with in their natural environment. Any additional resources should be made available so that this option can be realistically pursued.

4.4.9 If intervention in their current environment is not realistic then the person with disturbed behaviour should be placed in an alternative appropriate setting. This new setting should have extra resources which were not available in the previous setting such as better staff ratio, special training etc.

4.4.10 It is essential that crisis intervention placements should be available on a regular basis to families so that they can have a break when the need arises.

4.4.11 If possible, the practice of placing people with challenging behaviour together should be avoided.

4.4.12 A small percentage of people with very aggressive behaviour may need a safe restricted environment in order to prevent damage to themselves and others.

This environment should be as home-like as possible and should have a recorded treatment philosophy.

- 4.4.13 Experience has shown that the occurrence of psychiatric difficulties in people with mental handicap is greater than in the normal population. It is therefore important that they have the same right of access to appropriate psychiatric treatment whether on an inpatient or outpatient basis.
- 4.4.14 Services for children and adults with disturbed behaviour should not be provided in the same setting.
- 4.4.15 There is an urgent need for further training of staff and parents in order to help them deal more effectively with disturbed behaviour.
- 4.4.16 It is essential that every service for people with mental handicap should have a written policy on how it intends to deal with and treat people with disturbed behaviour.

4.4.17 SERVICES FOR THE ELDERLY

As people with mental handicap grow older the predominant problem may not be their mental handicap but the additional difficulties associated with old age.

- 4.4.18 It will be necessary to assess individually the needs of older people with a mental handicap. As far as possible their additional needs should be met by the normal geriatric services.

- 4.4.19 There should be a range of housing options and residential facilities available for elderly people with mental handicap. These could include :

- Housing provided by Mental Handicap Services.
- Nursing Homes.
- Special Housing Schemes for the elderly.

- 4.4.20 Elderly people with a mental handicap will need a range of day activities appropriate to their age group. Where possible these should be provided by the geriatric services.

4.5. AFTER CARE SERVICES

- 4.5.1 This section of the report refers mainly to people with mild mental handicap who broadly speaking have been discharged from the special classes in ordinary schools, special schools and training centres. They move into a variety of situations, for example, open employment or workshop activities and some due to the economic climate, move on to situations of inactivity - unemployment. Many of these people have either minimal or in some instances no supports available to them. It has been found that the ordinary community care structure has inadequate resources to support this group of people.

- 4.5.2. The Commission of Inquiry on Mental Handicap Report (17) states that the expectation for adults with mental handicap is for the majority to make satisfactory adjustment in independent living, for a minority to marry, and it is also recognised that a further minority require special services. The Cork Polio Research Group (18) found this to be true.

4.5.3 It is important to state that for those pupils who have no additional difficulties allied to their learning problems, the services are generally geared to equip them to integrate reasonably well in the community. However, when additional problems are present, for example, inadequate or no family support, emotional or psychiatric difficulties, physical disabilities, poverty, single parent-hood, accommodation problems, medical difficulties and marital/parenting problems, it has been found that such people have great difficulties in coping and integrating into society generally.

4.5.4 Unfortunately, no formal structure of after-care has been developed in this country as a whole. Ideally, the necessary supports should be available within normal community care structures. The reality is that personnel in this programme have very heavy demands on their time and have inadequate resources to deal with people with mental handicap in the community. Some agencies for people with mental handicap do make provision for their past attenders, but in general, it is not a well developed part of our services nationally.

4.5.5. The two main research studies in Ireland which focused on past pupils from mental handicap centres (19) (20) emphasise after-care as being a major gap in their services. In fact, the Cork Polio study identified 46% of the studied population to be in need of after-care.

4.5.6 The need for after-care is a familiar and a growing one especially in view of the well recognised fact that people with mental handicap mature at a slower rate than the rest of the population. It seems unwise to spend large sums of money on special education, care and training, and at the same time provide only limited or no after-care facilities. Indeed, many problems might be prevented or eased if follow up provisions were available.

4.5.7 In view of the pressing after-care needs it would be worth setting up a Feasibility Study in certain parts of the country, to ascertain whether a form of "open door" drop in centre could meet the needs of this group of people.

4.5.8 Such a centre could offer support through counselling, practical support, temporary accommodation etc. Such a service could reduce the sense of loneliness and isolation experienced by many people with mild mental handicap. It could offer a place where people could feel they belong, especially in view of the fact that a number of this group have no families or active family involvement.

4.5.9 The overall aim of such a provision would be to gradually assimilate this group back into mainstream society. A Feasibility Study like this, if well planned, could show good cost benefit returns.

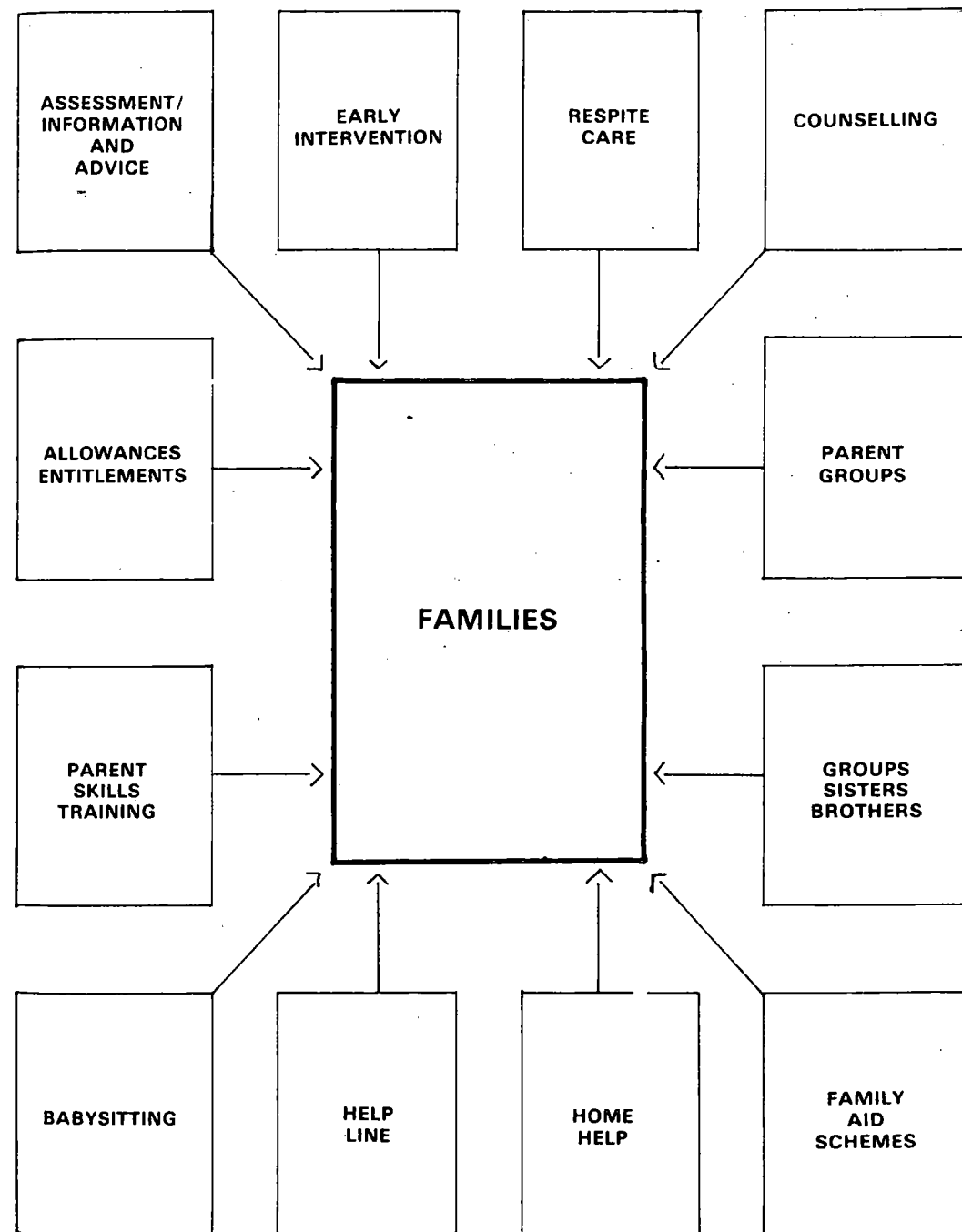
4.6. SUPPORTS TO FAMILIES

4.6.1 INTRODUCTION

Parents are rarely, if ever, prepared for hearing the news that their child has a mental handicap. In most instances this news comes as a major shock. Families usually experience a great sense of loss, isolation and often chronic sadness. Their confidence as parents is often affected. For most of them they soon realise that their responsibilities with a child with mental handicap are likely to persist throughout the life of the person with mental handicap, unlike the situation with a normal child who grows towards independence. Occasionally, the other children in the family can suffer especially when the parents, and mostly mothers, are fatigued with the constant caring needed by the child or adult with mental handicap. In essence the quality of life for the whole family can be effected.

4.6.2 Increasingly the emphasis is on people with mental handicap living in the community. The importance of supporting families in their endeavour to keep their adult/child with mental handicap living at home cannot be over emphasised. In order for families to cope effectively it is essential that we develop a very wide network of support services. The following are the key supports required by families (These are illustrated in Diagram 3).

DIAGRAM 3: Network of Supports for Families



4.6.3 NEED FOR INFORMATION, ASSESSMENT AND ADVICE

Parents need information on the nature and extent of the child's handicap. If specific medical factors are relevant it is crucial that parents have an opportunity to discuss these fully with a trained medical person. Parents also need information and advice about the most appropriate services that their particular child or adult will require. Families also need clear information about their entitlements to various allowances, aids and appliances, medical cover etc. (2). Families experience pressures at different times and go through various phases throughout the life of the person with mental handicap. Consequently they need to be supported with the advice and help from the various members of the multidisciplinary team throughout these various stages. In an interesting study of parents needs by the Daughters of Charity Services, it was noted that 811 of parents felt that the provision of legal advice to help plan their daughter/son's future was considered to be the most important information and advice service.

4.6.4 EARLY INTERVENTION

The importance of early intervention services cannot be overstated. For many parents it represents a lifeline, especially if a comprehensive range of supports are available. It is important therefore that Mental Handicap Agencies and Maternity Hospitals forge good links together so that babies are referred at the earliest possible stage.

4.6.5 Early intervention fulfills many functions :

- a) enables families to come to terms with the presence of a child with mental handicap. It can also prevent family breakdown.
- b) providing practical advice on how to handle and stimulate the child.
- c) identification of further handicaps and minimising their impact by early treatment.
- d) offers a multidisciplinary approach including when possible a specialist nurse in mental handicap.
- e) makes available some genetic counselling in the absence of comprehensive genetic counselling.

4.6.6 RESPIRE CARE

For many families the presence of a person with mental handicap can impose constant strain and worry, restrictions in social life and health difficulties. It is therefore, essential to alleviate stresses through making available a mix of respite care options appropriate for the individual person with mental handicap. For example; family placement schemes like 'Break Away' in Dublin and Louth - 'Home Sharing' in Galway - 'Have a Break Scheme' in Limerick and 'Share a Break Scheme' in the Midlands, crisis centres and residential care. Providing respite care in a well planned and preventative fashion will mean that people with mental handicap can remain living with their families and are less likely to require full time care. A major gap in this whole area is the lack of availability of short term placements for adults in particular.

It is very heartening to see St. Michael's House setting up a family placement scheme for adults called 'Home Choice'. Similar schemes will have to be developed in the future

4.6.7. COUNSELLING

Every family reacts differently to having a child with mental handicap. Counselling can be very effective in enabling families to deal with the emotional and practical aspects of adjusting to the person with mental handicap in their home. Peter Kieran in his article (22) highlights the work of Murtagroyd & Woolfe (1982) who describes how parents are facing the task of accepting the unacceptable. They also make reference to the initial crisis being a recurring one and one that lasts throughout the lifetime of the person with mental handicap. Counselling needs to involve not only the parents but also the other children in the family who also need to adjust to the changes brought about by the extra demands placed on the family by the presence of the child with mental handicap. In the Daughters of Charity Study (23) 67% of parents thought that more counselling should be provided.

4.6.8 PARENT GROUPS

Many parents tend to feel very isolated and alone in caring for their person with mental handicap. Having the opportunity of meeting other parents can reduce this sense of isolation by offering an opportunity to talk with others who have had a similar experience.

It can be very reassuring for parents to discover that their feelings of anger and rejection or guilt are not abnormal. The mutual support that parents can offer one another enhances greatly their ability to cope.

4.6.9 SISTERS AND BROTHERS

It is of crucial importance to involve and elicit the support of sisters and brothers in the care of the person with mental handicap. It is important to offer them an opportunity to participate as fully as possible in all aspects of the life of their sister or brother so that when the parents are no longer in a position to offer support the sisters and brothers will be available to the person with mental handicap.

4.6.10 FAMILY AID SCHEMES

The sheer practical aspects of caring for a child who has mental handicap within the family can be very exhausting especially for mothers. An effective community care structure must recognise the need to assist such families to ensure maximum functioning. A simple way of complementing the family's role in caring for their child/adult is to make a community helper available to the family for those times in the week when the family experience greatest need. The roles of such a support person can entail attending to the personal and developmental needs of the child, for example : feeding, washing, playing, bringing the child on outings etc.

The Crossroa Care Attendants Scheme set up in Britain in 1977 and the St. Michael's House Child Care Attendant Scheme are two examples of such schemes.

4.6.11 BABYSITTING

Many parents experience great difficulty in getting the usual babysitters to take on the care of a child with mental handicap. Many babysitters lack confidence and have unfounded fears and anxieties around caring for such a child. Community Care Services need to include babysitting as part of the network of supports for families.

4.6.12 HELP LINE

Many parents have expressed the need to have a twenty four hour 'Help Line' available to them. It is important that families should have a contact person available to them in times of personal crisis when coping mechanisms fail. Isolation can be a common denominator among many families.

4.6.13 PARENTING SKILLS TRAINING

Caring for a child with mental handicap places extra demands on parents. Often they have to learn new skills in order to cope with the child. Many parents have expressed the need to have well organised parent training courses to enhance their skills in coping with their child.

4.6.14 HOME HELP SERVICES

Many families experience difficulty in obtaining the ordinary services of a home help (the service provided by the Health Board).

This service would be invaluable to parents in freeing up their time so that they can give more attention to their child/adult with mental handicap.

4.6.15 INFORMATION

Clear information on allowances and entitlements should be made readily available to families.

4.6.16 ROLE OF FAMILIES

For the most part families have the primary caring role in relation to the child/adult with mental handicap in the community. It is heartening to see parents take a more active role in the development of policies and services in relation to mental handicap and to have a major influential role at this level. We would recommend the overall strengthening of family participation at all levels of Local, Regional and National planning.

4.6.17 SUMMARY

The importance of developing a comprehensive range of support networks for families cannot be overstated. Not all families will require all of the supports outlined above, however, it is important to have a wide range available so as to meet individual needs. These supports must be flexible in nature and represent a real attempt to translate the commitment of the ideal of community care into a reality. The numbers generally involved are quite small in any community care area. However, the benefits in terms of relieving intolerable strains on caring relatives can be extensive.

4.7. PRACTICAL SUPPORTS

4.7.1 A number of additional expenses can be incurred with the presence of a child/adult with mental handicap in a family. Many families require additional funding to cover costs of - special diets, transport costs, babysitting, additional clothing, extra washing costs, nappies, heating etc. An overview of the various entitlements and allowances are contained in Diagram 4.

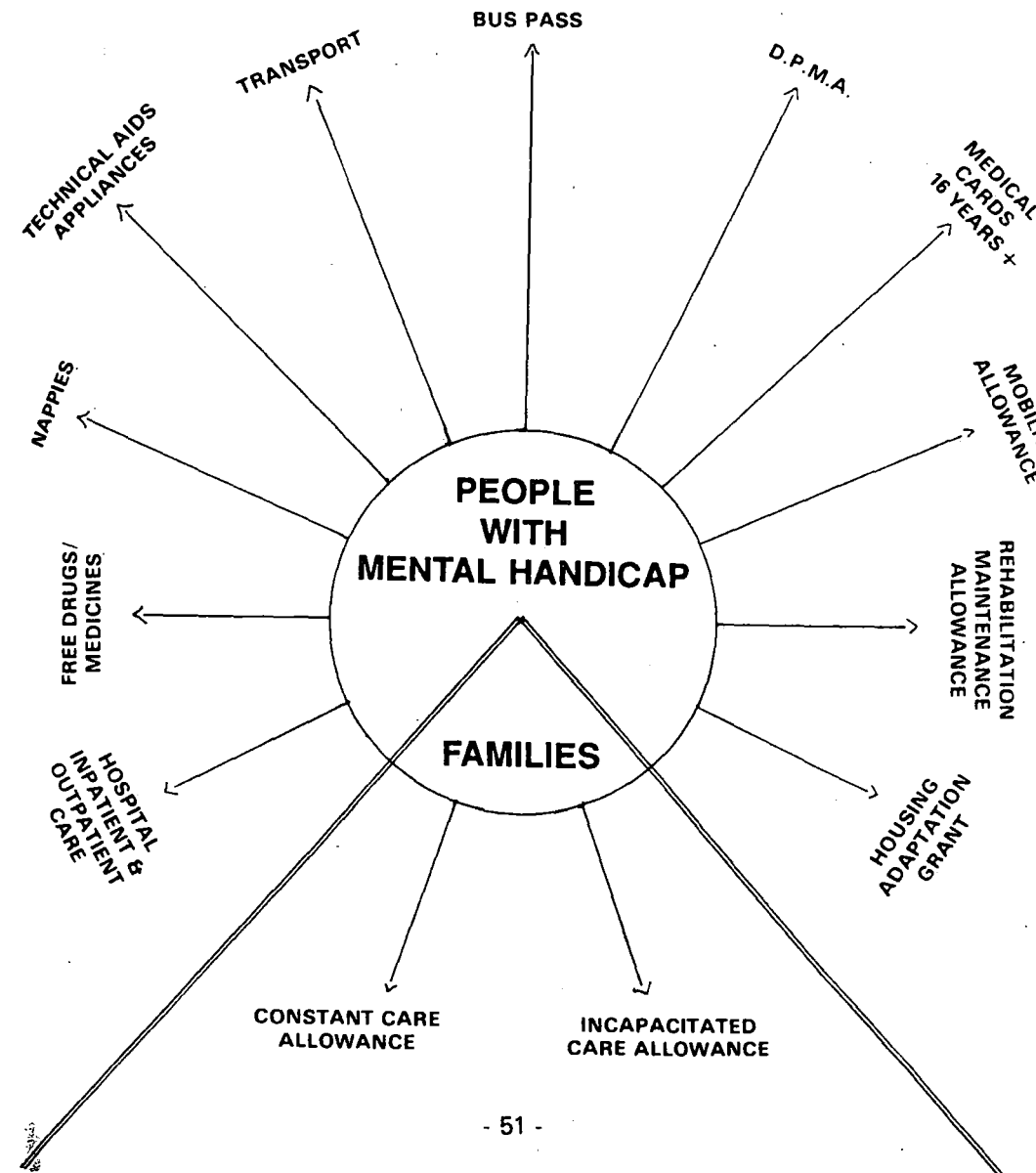
4.7.2 It is very evident that for many families the allowances and entitlements are insufficient to meet the full additional costs. For example all people in receipt of D.P.M.A. are entitled to a bus pass. However, adults who use wheelchairs little benefit because of our inaccessible transport system. The extra cost of hiring private accessible transport for social activities is prohibitive for many families.

4.7.3 A glaring inequity exists also in how allowances are administered. Evidence shows that variations exist between one Health Board and another.

4.7.4 In many areas families who have been granted the Constant Care Allowance are subjected to stringent reviews. Cutbacks in Health Boards have affected practical supports. For example many families have had their standard supply of nappies cut drastically, leaving them with no option but to purchase the additionally needed ones.

DIAGRAM 4:

ALLOWANCES and ENTITLEMENTS TO PEOPLE WITH MENTAL HANDICAP and THEIR FAMILIES



- 4.7.5 Another area of difficulty is the granting of the D.P.M.A. to people moving to community based residences. Local variation is evident with some Health Boards being reluctant to sanction the allowance.
- 4.7.6. The provision of a comprehensive range of practical supports to people with mental handicap is an essential component as part of a community care structure. We recommend that N.A.M.H.I. carefully monitor the administration of practical supports to ensure maximum equity and standardisation throughout the country.

SECTION 5 THE FUTURE - ESSENTIAL ELEMENTS

5.1.1. COMMUNITY AWARENESS.

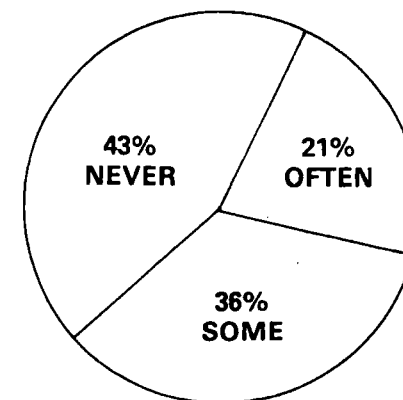
The lack of full integration of people with mental handicap in society reflects the insufficient level of their acceptance in the wider community.

- 5.1.2 People with mental handicap are one of a number of minority groups in society who have been devalued. For example, travelling people, ethnic minority groups, people with physical disabilities and people with mental illness have all suffered varying degrees of oppression within society.
- 5.1.3 The whole labelling process towards minority groups, including people with mental handicap, creates a barrier for the general public as well as doing a disservice to the individuals concerned.

- 5.1.4 During the early development of services in Ireland as in many other countries, an attitude of rejection and devaluation prevailed towards people with mental handicap. This attitude was reflected in the traditional segregated services which evolved.

- 5.1.5 Undoubtedly a major shift has been taking place in community attitudes. In general attitudes are mainly changed by direct contact with people with mental handicap. Therefore, the sheer increase in the numbers of people living in the community has contributed greatly to the changing of societies attitudes. This shift can also be attributed to the increasing involvement of ordinary people in the community with people with mental handicap.

- 5.1.6 In Roy Mc Conkey's book 'Breaking Barriers' (24), he reports on the national poll, conducted by the Market Research Bureau of Ireland, on behalf of the former Health Education Bureau 1981. It showed the frequency with which ordinary citizens were in contact with people with mental handicap) (See diagram)



These results are indeed disappointing with a 43% of citizens having no contact with people with mental handicap.

- 5.1.7 The need for community awareness is evident. The type of approach taken is vital to ensure acceptance. "Personal involvement and getting to know people over a long period of time has more influence on attitudes than factual information about mental handicaps. The former has the added advantage of dispelling any stereotype images and creating understanding and empathy, but ideally both, hand in hand, will be even more influential" (25).

In his book, Roy Mc Conkey includes a number of useful examples of community education programmes.

- 5.1.8 It is important that any community education programme be geared towards significant people/groups in community - e.g. educators, students, church leaders, politicians, and those involved in organisations for sport, leisure and social activities.

- 5.1.9 The coordination of such a programme should be under the auspices of N.A.M.H.I. and whatever additional help or expertise considered necessary should be recruited.

5.2. FUTURE OF RESIDENTIAL SERVICES

- 5.2.1 The reality within the Irish context is that we have inherited a number of large residential centres spread throughout the country. Many of them operate currently as part of the network of services.

- 5.2.2. The current trend of moving towards community care will mean moving many residents from large residential centres to alternative home options. This could permit the alternative use of such facilities.

- 5.2.3 The suggestions put forward for the future use of residential centres through the various consultation procedures of the Task Force were as follows :

- a) RESOURCE CENTRE - providing a variety of day facilities, specialist therapies etc.
- b) SPECIALIST PROVISION - e.g. for people with challenging (disturbed) behaviour.
- c) CRISIS CARE CENTRE - to provide short-term residential care.
- d) HIGH DEPENDANCY GROUPS - for people with severe and profound mental handicaps.
- e) CONVALESCENT UNIT - for those who need to recuperate from an illness.
- f) ELDERLY PEOPLE with mental handicap.
- g) HALF WAY HOUSE - for those who are inappropriately placed in psychiatric settings. The residential setting could be a stepping stone to the community.

5.3. RESEARCH

- 5.3.1 The availability of concrete information is essential for planning, organising and managing the activities of a service.

Therefore, it is advisable to have an efficient information system which can be readily updated.

- 5.3.2. For any service to be progressive, it is important that the needs of clients and ways of meeting them are constantly subjected to evaluation.
- 5.3.3. Having a research orientated approach to all aspects of service delivery brings clear objectivity by measuring effectiveness against stated aims and goals.
- 5.3.4. It is well recognised that staff who have an opportunity to evaluate their work in a systematic way usually have high performance levels. Ongoing research brings a constant freshness to a job and helps narrow the gap between theory and practice.

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23. McElvaney, R, Parents' Needs: A Survey.
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24. McConkey R, Mc Cormack B, Breaking Barriers
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25. Ibid.

SUBMISSIONS SENT TO
COMMUNITY CARE TASK FORCE

- . Brothers of Charity Services, Woodlands Centre, Galway.
- . Cheeverstown House, Dublin.
- . Co. Wexford Community Workshop (New Ross) Ltd.,
- . Cope Foundation, Cork (Formerly Cork Polio and General Aftercare Association).
- . Hospitaller Order of St. John of God, Dunmore House.
- . Kerry Parents and Friends of the Mentally Handicapped.
- . North Eastern Community Service, Hospitaller Order of St. John of God.
- . Occupational Therapists Special Interest Group in Mental handicap.
- . Organisation for Nurses of the Mentally Handicapped.
- . Peamount Hospital.
- . Psychological Society of Ireland.
- . Rehabilitation Institute, Cork.
- . St. Hilda's Services for the Mentally Handicapped, Westmeath.
- . St. Raphael's, Celbridge, Parents and Friends

- . Senior Speech Therapist, Eastern Health Board.
- . Social Work Department, Daughters of Charity Services, St. Vincent's Centre, Dublin.
- . Speech Therapists in Mental Handicap.
- . Social Workers in Mental handicap.